



**QUEEN'S  
UNIVERSITY  
BELFAST**

## Attitudes and Knowledge Concerning Corneal Donation in a Population-Based Sample of Urban Chinese Adults

Wang, X., Jin, L., Wang, J., Haid Garrett, E., Shuman, J., Yang, K., ... Congdon, N. (2016). Attitudes and Knowledge Concerning Corneal Donation in a Population-Based Sample of Urban Chinese Adults. *Cornea*, 35(10), 1362-1367. DOI: 10.1097/ICO.0000000000000943

**Published in:**  
Cornea

**Document Version:**  
Peer reviewed version

**Queen's University Belfast - Research Portal:**  
[Link to publication record in Queen's University Belfast Research Portal](#)

**Publisher rights**  
Copyright © 2016 Wolters Kluwer Health, Inc. All rights reserved.

**General rights**  
Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

**Take down policy**  
The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact [openaccess@qub.ac.uk](mailto:openaccess@qub.ac.uk).

1 Attitudes and Knowledge Concerning Corneal Donation in a Population-Based  
2 Sample of Urban Chinese Adults

3

4 Xiuqin Wang, MD,<sup>1,2</sup> Ling Jin, MS,<sup>1</sup> Jiawei Wang, MPA,<sup>1</sup> Elizabeth Haid Garrett,<sup>3</sup>  
5 Jeremy Shuman, MPH,<sup>3</sup> Ke Yang, MD,<sup>1,6</sup> Tim Schottman,<sup>3</sup> Tingting Chen, MD,<sup>1</sup> Jun  
6 Wang, MD,<sup>1</sup> Congyao Wang, MD,<sup>1</sup> and Nathan Congdon, MD, MPH<sup>1,4,5</sup>

7

8 1. State Key Laboratory of Ophthalmology and Division of Preventive Ophthalmology,  
9 Zhongshan Ophthalmic Center, Sun Yat-sen University, Guangzhou, Guangdong,  
10 China.

11 2. Affiliated Hospital of Guangdong Medical College, Zhanjiang, China.

12 3. SightLife, Seattle, WA, United States.

13 4. Orbis International, New York, NY, United States.

14 5. Translational Research for Equitable Eyecare, Center for Public Health, Queen's  
15 University Belfast, Belfast N. Ireland

16 6. Department of Ophthalmology, People's Hospital of Guangxi Zhuang Autonomous  
17 Region, Nanning, China

18

19 Correspondence: Nathan Congdon, State Key Laboratory of Ophthalmology and  
20 Division of Preventive Ophthalmology, Zhongshan Ophthalmic Center, Sun Yat-sen  
21 University, Guangzhou, People's Republic of China 510060; and TREE Centre,  
22 Centre for Public Health, Queen's University Belfast, 274 Grosvenor Rd, Belfast UK  
23 BT12 6BA; ncongdon1@gmail.com.

24 **Commercial Interest:** None of the authors has any commercial interest in the  
25 devices or techniques discussed in this article.

26

27 **Funding:** Sightlife, Seattle WA; Prof Congdon is supported by the Chinese  
28 government's Thousand Man Plan and by the Ulverscroft Foundation

29

30 **Key Words:** Cornea, transplant, donation, knowledge and attitudes, China

31

32 **MS Length:** 2581 words, 5 tables. Abstract: 247 words

33

34 **Version:** 20 May 2016

35 **Abstract**

36 **Purpose** To better understand knowledge and attitudes concerning corneal donation  
37 among Chinese adults.

38 **Methods** Randomly-selected residents in pre-determined age strata 20-60+ years  
39 completed home-based questionnaires in each of 12 randomly-chosen communities  
40 in Guangzhou, southern China.

41 **Results** Among 1,217 selected persons, 430 (35.3%) completed questionnaires  
42 (mean age 40.4 years, 57.9% female). Refusers were older (44.8 years,  $p < 0.001$ ),  
43 but gender makeup did not differ (52.2% female,  $P = 0.07$ ). Among participants, 175  
44 (40.7%) were willing to donate their corneas (WTD). Differences between WTD and  
45 not WTD included: donation knowledge score (range 1-12) (WTD (Standard  
46 Deviation, SD)  $6.91 \pm 2.21$ , not WTD  $5.62 \pm 2.43$ ,  $p < 0.001$ ); having discussed  
47 donation (WTD 26.3%, not WTD 8.63%,  $p < 0.001$ ); viewing donation as unpopular  
48 (WTD 88.0%, not WTD 96.5%,  $p = 0.001$ ); and feeling donation “damages the body”  
49 (WTD 15.4%, not WTD 25.7%,  $p = 0.013$ ). Associated significantly with WTD in  
50 multiple regression models were: higher knowledge score (OR=1.18, 95% CI 1.04,  
51 1.32,  $P = 0.008$ ); not feeling donation “damages the body” (OR=1.91, 95% CI 1.07,  
52 3.43,  $p = 0.030$ ); and willingness to discuss donation (OR=10.6, 95% CI 3.35, 33.9,  
53  $p < 0.001$ ). WTD did not differ by age (>60 years: 22/51, 43.1%; ≤60 years: 153/379,  
54 40.4%,  $p = 0.706$ ). Assuming all refusing the survey would not donate, 14.4%

55 (175/1217) were WTD for themselves, though only 7.1% (86/1217) would do so on  
56 behalf of a family member if they did not know the deceased's preference.

57 **Conclusions** Interventions to increase knowledge and promote discussions about  
58 donation, as well as policies allowing widespread expression of donation preference,  
59 are needed in this setting.

## 60 **Introduction**

61 Corneal opacity is among the world's leading cause of blindness, ranking behind  
62 cataract, glaucoma and AMD, but ahead of diabetic retinopathy.<sup>1</sup> Over 1.5 million  
63 persons are blind from corneal opacity, accounting for some 4% of all global  
64 blindness.<sup>1</sup> In China, the impact of corneal blindness is even greater, accounting for  
65 10-15% of all blindness and ranking among the top three causes.<sup>2, 3</sup> The overall  
66 burden of corneal blindness is further increased when trachoma is included, though  
67 non-trachomatous causes are more likely to be treatable.<sup>4</sup>

68 It has been estimated that 80% of corneal blindness is preventable.<sup>4</sup>  
69 Nonetheless, transplantation surgery is a highly-effective option for many persons  
70 suffering from corneal blindness, with overall long-term success rates as high as 80-  
71 90%.<sup>5, 6</sup> While 50,000 corneal transplantations are performed annually in the United  
72 States,<sup>4</sup> in China, with its far larger population and higher prevalence of blinding  
73 corneal disease, only about 5000 such surgeries are done each year.<sup>7, 8</sup> The principal  
74 limitation is a lack of donor tissue,<sup>7</sup> a requirement for all of the various types of  
75 corneal transplant surgery commonly performed today.<sup>4</sup>

76 Practical barriers to corneal donation have been described as including lower  
77 educational and economic levels, older age, lack of knowledge about the process  
78 and specific cultural beliefs inconsistent with donation.<sup>8-10</sup> Previous studies on  
79 donation of other tissues besides cornea among persons of Chinese heritage on

80 have highlighted important barriers related to specific Chinese cultural beliefs: the  
81 body is traditionally thought of as a gift from the parents, which should not be  
82 damaged or altered, even after death.<sup>11-13</sup> Additionally, concerns about mis-use or  
83 sale of donated tissue, presumably reflecting a more widespread lack of trust in the  
84 medical system, has been identified as a barrier.<sup>11, 13, 14</sup> Finally, under Chinese law,<sup>15</sup>  
85 next-of-kin must agree to donation of any organ after death, even if the deceased has  
86 clearly expressed a wish to donate.<sup>16</sup> Though the law nominally applies only to organ  
87 donation and not tissues such as the cornea, in actual fact, eye banks in China also  
88 follow this practice. This de facto veto power on the part of immediate relatives  
89 means that their attitudes play a very significant role in donation, and must be  
90 understood.

91        Though knowledge and attitudes among ethnically Chinese persons about organ  
92 and tissue donation, including corneas, have been studied,<sup>11, 12, 14, 17-21</sup> few  
93 investigations<sup>11</sup> have taken a population approach in order to better understand the  
94 situation in the community at large, and none of these population studies have  
95 focused on corneal donation. Further, those few studies of corneal donation in China  
96 have not generally focused on knowledge and attitudes of potential donors. In the  
97 current manuscript, we describe knowledge and attitudes towards corneal donation  
98 for oneself and for close relatives in a population-based sample of urban Chinese  
99 residents in Guangzhou, southern China, selected to include a pre-determined  
100 number of respondents across various age strata. Our hypothesis was that younger

101 persons would be significantly more receptive to donation for themselves and family  
102 members, and less influenced by traditional Chinese cultural attitudes.

103 **Materials and Methods**

104 This project was carried out as part of the preparation for SightLife, a US-based  
105 non-governmental organization focusing on corneal transplantation, to initiate  
106 programs in China. The protocol for this study was approved in full by the Ethics  
107 Committee at Zhongshan Ophthalmic Center, Sun Yat-sen University (Guangzhou,  
108 China). Written informed consent was given by all participants, and the principals of  
109 the Declaration of Helsinki were followed throughout.

110 **Sampling and Enrollment Criteria**

111 Among nine municipal districts (Yuexiu, Liwan, Tianhe, Baiyun, Luogang, Haizhu,  
112 Nansha, Panyu and Huangpu) comprising Guangzhou city, southern China, three  
113 were selected at random (Liwan, Tianhe and Panyu). Twelve communities were  
114 randomly selected from among a total of 484 in the selected three districts. A registry  
115 of residencies was obtained from the local government, including approximately  
116 13,000 households. A household was selected at random as a starting point, and  
117 then every tenth household in the community was selected. In each household, one  
118 person was selected using a random number table, with enrollment continuing  
119 until  $\geq 35$  persons had been enrolled in the community, including a minimum of 5  
120 persons in each age stratum 20-30, 31-40, 41-60 and  $> 60$  years. The only exclusion  
121 criteria were physical or mental conditions precluding completing the questionnaire or  
122 giving informed consent.



## 123 Questionnaire

124 The questionnaire used in the current study was adapted from Lawlor et al,<sup>10</sup> due  
125 to that study's focus on the impact of views on disfigurement and knowledge about  
126 the donation process on attitudes towards and acceptance of donation. The  
127 questionnaire used in the current study contained 36 items arranged in eight  
128 sections: (1) Demographic information, (2) Knowledge and awareness of corneal  
129 donation, (3) Social group influences, (4) Perceived benefits of donation, (5) Barriers  
130 to donation, (6) Cultural attitudes, (7) Willingness to donate and (8) Motivators toward  
131 donation.

132 The investigators were aware that questions concerning the death of a loved one  
133 are highly culturally sensitive in China, and that careful wording of the questionnaire  
134 would be needed to avoid very high refusal rates in the setting of a door-to-door  
135 survey. Two pilot studies were conducted to test the sensitivity of the questionnaire  
136 and adjust wording as needed before the full study began. In each pilot, ten residents  
137 of Guangzhou City aged 20 to 60 years were identified in clinics and offices at  
138 Zhongshan Ophthalmic Center. In the first, respondents were requested to answer  
139 an early draft of the questionnaire, with refusals to answer individual questions being  
140 recorded. In the second pilot, respondents were asked to grade the sensitivity of  
141 each question on a revised draft using a Likert scale (5 Very uncomfortable to  
142 answer to 1 Very comfortable to answer), without actually responding to questions.

143 On the basis of the two pilots, the most sensitive questions were eliminated  
144 altogether, sensitive wording was replaced (“die” with “pass away,” “cornea” with  
145 “material”, etc.) and the order of the questions was rearranged to place the most  
146 sensitive questions at the end.

#### 147 **Data collection**

148 Trained, experienced investigators from a local government-affiliated survey firm  
149 made a total of three attempts to contact each household identified as above  
150 (Sampling and Enrollment) by knocking on the door. Age and gender were recorded  
151 for all persons refusing participation in the survey, and those agreeing to take part  
152 were requested to complete the survey on the spot. Respondents answered  
153 questions on their own, without discussing the contents with the interviewers, who  
154 answered questions as needed.

#### 155 **Statistical Methods**

156 The total population of Guangzhou City at the end of 2011 (the most recent year  
157 available) according to household registers was 8,145,797.<sup>22</sup> The sample size for the  
158 survey was calculated using the formula:  $N = [(2 * Z^{\alpha/2} * P * (1-P)) / (MOE^2)] * Deff$ , where  $\alpha$   
159 represented a Type I error of 0.05,  $P=0.4$  was the estimated rate of willingness to  
160 donate,  $MOE=0.06$  was the margin of error (maximum tolerated error) and  $Deff = a$   
161 design effect of 1.5, describing the loss of sampling efficiency due to use of a cluster  
162 sampling design. Two publically-available websites<sup>23, 24</sup> were used to carry out the

163 calculations, and gave identical results: 384 valid respondents were required for the  
164 survey according to the above parameters. Adjusting for an expected non-response  
165 rate of 65% based on experience of the firm with similar door-to-door surveys, the  
166 expected number of persons needed to be contacted  $384/0.35 = 1097$  persons.

167 The main outcome of the study was the willingness of the respondent to donate  
168 his/her own cornea. A secondary outcome was willingness to donate on behalf of a  
169 relative. Both questions required a definite yes or no answer. Age and sex were  
170 compared between those accepting and refusing participation in the survey. Basic  
171 demographic characteristics, knowledge and attitudes were compared between those  
172 who would and would not donate. Multiple logistic regression models were used to  
173 assess the relationship between the main outcome of willingness to donate and  
174 potential predictors. The motivators and statements selected by respondents from a  
175 prepared list as playing a role in their willingness or unwillingness to donate their own  
176 corneas or those of family members were ranked by the proportion of participants  
177 selecting them. Analyses were performed using Stata 12.0 (StataCorp, College  
178 Station, TX) using the survey features, which account for the effects of cluster  
179 sampling.

180

181 **Results**

182 A total of 1217 persons were randomly selected for investigation. Among these,  
183 787 (64.7%) refused participation, and 430 (35.3%) accepted. Refusers had a mean  
184 age  $\pm$  SD of  $44.8 \pm 13.8$  years, and 408 (52.2%) were female, while participants were  
185 significantly younger ( $40.4 \pm 15.6$  years,  $P < 0.001$ ) but did not differ significantly by  
186 gender makeup. (Table 1) Among participants, 175 (40.7% of enrollees, 14.4% of  
187 total) indicated they would be willing to donate their own cornea (WTD). Their age,  
188 gender, religion, education, income, marriage status and role in parents' medical care  
189 did not differ significantly from those ( $n=255$ , 59.3%) who would not donate (Table 2).

190 Table 3 summarizes differences in knowledge and attitude between those who  
191 would and would not donate. Significant differences included: donation knowledge  
192 score (WTD mean knowledge score  $\pm$  SD  $6.91 \pm 2.21$  on a scale of 1-12, not WTD  
193  $5.62 \pm 2.43$ ,  $p < 0.001$ ); having ever discussed donation (WTD 26.3%, not WTD  
194 8.63%,  $p < 0.001$ ); viewing donation as "unpopular" in society (WTD 88.0%, not WTD  
195 96.5%,  $p = 0.001$ ); feeling donation "damages the body" (WTD 15.4%, not WTD  
196 25.7%,  $p = 0.013$ ); being "unlikely" to discuss donation (WTD 67.4%, not WTD 98.0%,  
197  $p < 0.001$ ); and "unlikely" to permit donation of a relative's corneas (WTD 60.6%, not  
198 WTD 95.7%,  $p < 0.001$ ). Those willing and unwilling to donate did not differ in the  
199 perception that donated material may be frequently misused in China (WTD 28.0%,  
200 not WTD 33.7%,  $P = 0.206$ ).

201 In multiple logistic regression models of potential determinants of WTD (Table 4),

202 the following remained significant: having higher knowledge score (OR=1.18, 95%  
203 confidence interval [CI], 1.04-1.32, P=0.008), not feeling donation “damages the  
204 body” (OR=1.91, 95% CI, 1.07-3.43, p=0.030), willingness to discuss donation  
205 (OR=10.6, 95% CI, 3.35-33.9, P<0.001), and being likely to give consent for donation  
206 of a family member’s corneas (OR=10.3, 95% CI, 4.84-21.8; P<0.001) (Table 4).

207 Respondents were asked about willingness to consent for donation of a loved  
208 one’s corneas under two different circumstances: 48.4% (207/428) would consent if  
209 they knew that the deceased had wished it, while 20.2% (86/426) would do so if  
210 unaware of the wishes of the deceased (answers were not provided by two and four  
211 respondents under the first and second scenario respectively). Responses were not  
212 associated with the age or gender of the respondent under either scenario, and  
213 predictors of a positive response in regression models were similar to those for  
214 willingness to donate on one’s own behalf (data not shown).

215 The four most important reasons for not being willing to donate one’s cornea or  
216 consent to donation on behalf of a family member were: “I do not like thinking about  
217 death” (49% self, 33% relative); “I am concerned the materials might be bought and  
218 sold on the black market” (45% self, 38% relative); “I would just not feel comfortable  
219 about it” (40% self, 35% relative); and “I feel the body should be buried whole” (35%  
220 self, 58% relative). (Table 5) (Data on consent on behalf of a family member are not  
221 shown.) The most popular statements identified as playing a role in being willing to  
222 donate one’s own cornea included “two blind people can see again” (57.1%), “Allows

223 something positive to come out of the donor's life" (46.3%) and "Feel like I am part of  
224 solving blindness problems in my community" (41.7%). The most popular specific  
225 motivators for donation of one's own corneas included donor family support groups  
226 (32.6%), thank you letters from recipients (30.9%) and thank you letters from the eye  
227 bank (26.9%) (Table 5, on line only)

228

229 **Discussion**

230 While over 40% of participants in the current study indicated they would be willing  
231 to donate their own corneas, this result must be placed in the context of the high  
232 refusal rate (nearly two-thirds) among those selected on a population basis.  
233 Assuming that all those refusing to take part would also have refused to donate, the  
234 proportion willing to donate would still be 14.4% (175/1217). It must also be  
235 remembered, however, that under current Chinese law<sup>15</sup> and eye banking practices,  
236 family members have a de facto veto power over donation of a deceased relative's  
237 organs and tissues. While respondents were even more willing (48.4% versus  
238 40.7%) to authorize donation on behalf of a deceased relative than for themselves  
239 when they knew the deceased approved of donation, the proportion was less than  
240 half this (20.2%) when the preference of the deceased was not known. As only  
241 16.1% of all respondents had ever had a conversation about donation, this makes it  
242 more likely that the wishes of a deceased potential donor would not be known by  
243 family members. Applying the conservative assumption that all refusing participation  
244 in this survey would have been unwilling to authorize donation on behalf of a loved  
245 one, and that none were certain of the preferences of the deceased, we may  
246 estimate that 7.1% (86/1217) of persons in this Chinese urban setting might agree to  
247 donation of a deceased relative's corneas.

248 These results have implications for Chinese policy-makers seeking to increase  
249 the amount of corneal tissue available for transplant. As outlined above, allowing

250 persons to make their own choice for donation prior to death could potentially double  
251 the rate of positive responses compared to a relative deciding on behalf of a  
252 decedent whose wishes s/he did not know. Effective and widespread programs  
253 allowing individuals to record their donation wishes, and policies requiring that those  
254 wishes be honored when clearly stated, would appear to be effective options to  
255 increase donation. In the United States for example, a desire to donate can be  
256 expressed at the time of registration for a driver's license in many states,<sup>25</sup> and  
257 similar policies exist in other countries as well,<sup>10, 26</sup> though few with cultural beliefs  
258 about the sanctity of the body such as exist in China. In the United States;<sup>25, 27</sup> and  
259 in many European countries,<sup>28</sup> organ donation can be authorized with the  
260 individual's own consent, without requiring that the family agree. Various countries in  
261 the European Union, Wales being the earliest,<sup>28</sup> have some form of presumed  
262 consent, also referred to as an "opt-out system," which has led in settings such as  
263 Spain to rates of cadaveric organ donation (33.6 per million inhabitants), and kidney  
264 and liver transplantation (50.6 and 24.2 per million respectively), which are among  
265 the highest in the world.<sup>29, 30</sup>

266       Regarding other predictors of willingness to donate and their implications for  
267 program design, our hypothesis that younger respondents would be more willing to  
268 donate proved to be untrue for either self-donation or authorization on behalf of a  
269 relative. The association between donation and both greater knowledge about, and a  
270 willingness to discuss, the process suggests that interventions to increase donation



271 might focus on education and promoting family discussions. Results from the Barriers  
272 and Motivators sections of the study can also inform future programs: concern over  
273 misuse of tissue is a top-ranking concern with regard to both self-donation and that  
274 on behalf of relatives. Efforts to make the donation process highly transparent and  
275 eye banks fully accountable are needed, together with public education aimed at  
276 promoting these ideas. Motivators ranked highly by respondents, such as donor  
277 family support groups and thank you letters, may also be useful to increase donation.

278 In accord with other studies,<sup>11</sup> the current report underscores the fact that  
279 donation is a very sensitive topic in China. High proportions of respondents find  
280 thoughts or discussions about death and donation uncomfortable and unwelcome,  
281 while still subscribing to the idea that the body should remain intact in death.  
282 Nonetheless, if our calculations above are correct that one in fourteen persons in this  
283 setting might authorize donation on behalf of a relative, then programs which actively  
284 contact bereaved families to seek consent may be practical at sufficiently large  
285 hospitals. While such programs are common in the United States and Europe,  
286 donation in China generally depends on relatives to take the initiative. We have  
287 begun a pilot program to train donation coordinators at two hospitals in Guangdong  
288 Province for family outreach, and plan to test interventions based on findings of the  
289 current study using a randomized controlled design in these pilot projects.

290 The main strength of the current study is its population design involving  
291 community-residing persons over a wide age range, together with the relatively

292 detailed questionnaire. A principal weakness is the high refusal rate, despite  
293 considerable effort to frame the questionnaire in an inoffensive way. While home  
294 surveys may be prone to yield such high refusal rates, it has been suggested that the  
295 impact on representativeness of the sample may not be large.<sup>31</sup> Additional  
296 weaknesses include the fact that participants were speculating about their response  
297 in the event of the death of a loved one, rather than being interviewed after an actual  
298 such occurrence. We hope to address this shortcoming in future work.

299 Despite these limitations, this is first population-based study of attitudes towards  
300 corneal donation in China, and it provides useful information for project planners  
301 seeking to start programs in that challenging setting.

302 **Acknowledgements**

303 **Funding** Financial Supported by SightLife (Seattle, WA), Prof Congdon is supported  
304 by the Chinese government Thousand Man Plan and by the Ulverscroft Foundation.

305

306 **References**

- 307 1. Pascolini D, Mariotti SP. Global estimates of visual impairment: 2010. *Br J*  
308 *Ophthalmol* 2012;96:614-618.
- 309 2. Liang Y, Friedman DS, Wong T, et al. Prevalence and causes of low vision and  
310 blindness in a rural chinese adult population: the Handan Eye Study. *Ophthalmology*  
311 2008;115:1965-1972.
- 312 3. Xu L, Wang Y, Li Y, et al. Causes of blindness and visual impairment in urban and  
313 rural areas in Beijing: the Beijing Eye Study. *Ophthalmology* 2006;113:1134-1141.
- 314 4. Lamm V, Hara H, Mammen A, et al. Corneal blindness and xenotransplantation.  
315 *Xenotransplantation* 2014;21:99-114.
- 316 5. Thompson RW Jr, Price MO, Bowers PJ, et al. Long-term graft survival after  
317 penetrating keratoplasty. *Ophthalmology* 2003;110:1396-1402.
- 318 6. Borderie VM, Boelle PY, Touzeau O, et al. Predicted long-term outcome of corneal  
319 transplantation. *Ophthalmology* 2009;116:2354-2360.
- 320 7. Zhang M. Strategies to resolve the problem of lack of keratoplasty materials in  
321 China. *Chin J Ophthalmol* 2007;43:289-292. (Chinese)
- 322 8. Afshar R, Sanavi S, Rajabi M. Attitude and willingness of high school students  
323 toward organ donation. *Saudi J Kidney Dis Transpl* 2012;23:929-933.
- 324 9. McGlade D, McClenahan C, Pierscionek B. Attitudes underlying corneal donation  
325 in a group of trainee allied health professionals. *PloS One* 2012;7:e53538.
- 326 10. Lawlor M, Kerridge I, Ankeny R, et al. Specific unwillingness to donate eyes: the

- 327 impact of disfigurement, knowledge and procurement on corneal donation. *Am J*  
328 *Transplant* 2010;10:657-663.
- 329 11. Yeung I, Kong SH, Lee J. Attitudes towards organ donation in Hong Kong. *Soc*  
330 *Sci Med.* 2000;50:1643-1654.
- 331 12. Chu T, Wang L, Yu H, et al. Awareness of cornea donation of registered tissue  
332 donors in Nanjing. *Chin Med Sci J* 2013;28:20-27.
- 333 13. Xie S, Woo SM, Zhang L. Strategies for changing negative public attitudes toward  
334 organ donation in the People's Republic of China. *Patient Prefer Adherence* 2014;8:25-  
335 30.
- 336 14. Chen J, Zhang T, Lim F, et al. Current knowledge and attitudes about organ  
337 donation and transplantation among Chinese university students. *Transplant Proc*  
338 2006;38:2761-2765.
- 339 15. Decree of the State Council of the people's Republic of China (No. 491st) -  
340 human organ transplantation Ordinance. Available at:  
341 <http://www.moh.gov.cn/mohzcfgs/pfg/200804/29213.shtml>. Accessed September 24,  
342 2015 (Website in Chinese.)
- 343 16. China human organ donation registration process. Available at:  
344 <http://www.rcscod.org.cn/articleDetailView.shtml?articleId=ff808081453f2d1301453f3408d70008&moduleId=2c90a85f4110a883014110af55500003&moduleType=2&siteId=ff808181126bebda01126bec4dd00001>. Accessed October 4, 2015 (Website in  
346 Chinese.)  
347 Chinese.)

- 348 17. Wu AMS, Tang CS. The negative impact of death anxiety on self-efficacy and  
349 willingness to donate organs among Chinese adults. *Death Stud* 2009;33:51-72.
- 350 18. Liu Y, Lei H, Qui F. Investigation of attitudes towards organ transplantation in young  
351 people in China. *Chin Med J (Engl)* 1997;110:210-215.
- 352 19. Tam WW, Suen LK, Chan HY. Knowledge, attitudes and commitment toward organ  
353 donation among nursing students in Hong Kong. *Transplant Proc* 2012;44:1196-1200.
- 354 20. Hu D, Huang H. Knowledge, Attitudes, and Willingness Toward Organ Donation  
355 Among Health Professionals in China. *Transplantation* 2015;99:1379-1385.
- 356 21. Zhang L, Li Y, Zhou J, et al. Knowledge and willingness toward living organ  
357 donation: a survey of three universities in Changsha, Hunan Province, China.  
358 *Transplant Proc* 2007;39:1303-1309.
- 359 22. Registered Households and Population at Year-end by District and County-level  
360 City (2011). Available at: <http://data.gzstats.gov.cn/gzStat1/chaxun/njsj.jsp>. Accessed  
361 September 24, 2015 (Website in Chinese.)
- 362 23. WHO | STEPS Sample Size Calculator and Sampling Spreadsheet. Available  
363 at: <http://www.who.int/chp/steps/resources/sampling/en/>. Accessed September 24,  
364 2015.
- 365 24. Sample size calculator. Available at: <http://www.raosoft.com/samplesize.html>.  
366 Accessed September 24, 2015.
- 367 25. Nathan HM, Conrad SL, Held PJ, et al. Organ donation in the United States. *Am*  
368 *J Transplant* 2003;3:29-40.

- 369 26. Wellesley H. A nudge in the right direction for organ donation--but is it enough?.
- 370 *BMJ* 2011;343:d5726
- 371 27. Orentlicher D. Presumed consent to organ donation: its rise and fall in the United
- 372 States. *Rutgers Law Review* 2009;61:295-331.
- 373 28. UK Transplant Laws. Available at: [http://www.organdonationscotland.org/uk-](http://www.organdonationscotland.org/uk-transplant-laws)
- 374 [transplant-laws](http://www.organdonationscotland.org/uk-transplant-laws). Accessed November 2, 2015.
- 375 29. Matesanz R. A decade of continuous improvement in cadaveric organ donation:
- 376 the Spanish model. *Nefrologia* 2001;21:59-67.
- 377 30. Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ
- 378 donation: a cross country study *J Health Econ* 2006;25:599-620.
- 379 31. Holbrook AL, Krosnick JA, Pfent A. The Causes and Consequences
- 380 of Response Rates in Surveys by the News Media and Government Contractor Survey
- 381 Research Firms. *Advances in Telephone Survey Methodology*. New York: John Wiley
- 382 & Sons, Inc. 2008:499-678.

**Table 1: Basic demographic information for those accepting and refusing participation in the survey**

<b>Characteristics</b>	<b>All (N = 1217)</b>	<b>Refuse participation (N = 787, 64.7%)</b>	<b>Accept participation (N = 430, 35.3%)</b>	<b>P-value comparing refusing vs. accepting participation*</b>
<b>Age, y, n (%)†</b>				<0.001
20–30	352 (29.0)	200 (25.6)	152 (35.4)	
31–40	258 (21.3)	169 (21.6)	89 (20.7)	
41–50	274 (22.6)	196 (25.1)	78 (18.1)	
51–60	200 (16.5)	140 (17.9)	60 (14.0)	
>60	128 (10.6)	77 (9.85)	51 (11.9)	
Mean (SD)	43.2 (14.6)	44.8 (13.8)	40.4 (15.6)	
<b>Sex, n (%)‡</b>				
Female	657 (54.2)	408 (52.2)	249 (57.9)	0.070
Male	554 (45.8)	373 (47.8)	181 (42.1)	

\* Taking the effects of cluster sampling into account, simple linear regression was used for age and logistic regression was used for sex to compare the difference between groups.

†: 5 (0.41%) persons who refused participation had missing data for age.

‡: 6 (0.49%) persons who refused participation had missing data for sex.



**Table 2: Demographic information by willingness to donate**

Characteristics	All (N=430)	Would donate (n = 175)	Would not donate (n = 255)	P-value‡
<b>Age, y, n (%)</b>				0.699
20–30	152 (35.3)	58 (33.1)	94 (36.9)	
31–40	89 (20.7)	41 (23.4)	48 (18.8)	
41–50	78 (18.1)	29 (16.6)	49 (19.2)	
51–60	60 (14.0)	25 (14.3)	35 (13.7)	
>60	51 (11.9)	22 (12.6)	29 (11.4)	
Mean (SD)	40.4 (15.6)	40.7(15.4)	40.1 (15.7)	
<b>Sex, n (%)</b>				0.597
Female	249 (57.9)	104 (59.4)	145 (56.9)	
Male	181 (42.1)	71 (40.6)	110 (43.1)	
<b>Religion, n (%)</b>				0.741
None	369 (85.8)	149 (85.1)	220 (86.3)	
Buddhist/Christian/Other	61 (14.2)	26 (14.9)	35 (13.7)	
<b>Education, n (%)*</b>				0.246
None/Elementary school	52 (12.1)	16 (9.14)	36 (14.2)	
Junior school	168 (39.2)	66 (37.7)	102 (40.2)	
High school	112 (26.1)	47 (26.9)	65 (25.6)	
College or above	97 (22.6)	46 (26.3)	51 (20.1)	
<b>Income, RMB per month, n (%)†</b>				0.149
< 2000	104 (24.5)	38 (21.8)	66 (26.4)	
2000-4000	197 (46.5)	75 (43.1)	122 (48.8)	
4001-6000	86 (20.3)	43 (24.7)	43 (17.2)	
>6000	37 (8.73)	18 (10.3)	19 (7.60)	
<b>Marriage status, n (%)</b>				0.482
Married and living with spouse	309 (71.9)	129 (73.7)	180 (70.6)	
Single	121 (28.1)	46 (26.3)	75 (29.4)	
<b>Role in parents' medical care, n (%)§</b>				
No living parents	73 (17.0)	34 (19.4)	39 (15.3)	0.262
Have living parents, takes an active role	122 (28.4)	45 (25.7)	77 (30.2)	0.311
Have living parents, but takes no role	212 (49.3)	86 (49.1)	126 (49.4)	0.956
Spouses' parents living, takes an active role	70 (16.3)	26 (14.9)	44 (17.3)	0.508
Spouses' parents living, takes no role	174 (40.5)	72 (41.1)	102 (40.0)	0.812

\*: 1 (0.23%) person unwilling to donate group had missing education data.

†: 6 (1.40%) persons (1 willing and 5 unwilling to donate) had missing income data.

‡: Taking the effects of cluster sampling into account, simple linear regression was used for age, ordinal logistic regression was used for education and income, and logistic regression was used for all other variables in comparing the difference between groups.

§: Participants could select more than one choice, so the total numbers exceeded 430.

**Table 3: Knowledge and attitudes among those who would and would not donate**

Item	Would Donate (n=175)	Would not Donate (n=255)	P-value comparing would vs. would not donate*
<b>Knowledge summary score, Mean (SD) †</b>	6.91 (2.21)	5.62 (2.43)	<0.001
<b>Ever had conversation about donation, n (%)</b>			<0.001
Yes	46 (26.3)	22 (8.63)	
No	129 (73.7)	233 (91.4)	
<b>Social and cultural attitudes, n (%)</b>			
<b>Corneal donation is generally popular in society</b>			0.001
Not sure/disagree/strongly disagree	154 (88.0)	246 (96.5)	
Agree/strongly agree	21 (12.0)	9 (3.53)	
<b>The body is a gift from the parents‡</b>			0.476
Not sure/disagree/strongly disagree	15 (8.57)	27 (10.7)	
Agree/strongly agree	160 (91.4)	226 (89.3)	
<b>Donation damages the body‡</b>			0.013
Not sure/disagree/strongly disagree	148 (84.6)	188 (74.3)	
Agree/strongly agree	27 (15.4)	65 (25.7)	
<b>Donated material may be frequently misused in China§</b>			0.206
Not sure/disagree/strongly disagree	126 (72.0)	167 (66.3)	
Agree/strongly agree	49 (28.0)	85 (33.7)	
<b>Attitudes towards discussion and proxy consent, n (%)</b>			
<b>Willing to discuss donation</b>			<0.001
Not sure/disagree/strongly disagree	118 (67.4)	247 (98.0)	
Agree/strongly agree	57 (32.6)	5 (1.98)	
<b>Likely to give consent to donate a loved one's cornea‡</b>			<0.001
Not sure/disagree/strongly disagree	106 (60.6)	242 (95.7)	
Agree/strongly agree	69 (39.4)	11 (4.35)	

\* Taking the effects of cluster sampling into account, simple linear regression was used for knowledge score and logistic regression was used for all other variables in comparing the difference between groups.

†: 8 (1.86%) persons had missing data.

‡: 2 (0.46%) persons had missing data.

§: 3 (0.70%) persons had missing data.

**Table 4: Multiple logistic regression model of potential determinants of willingness to donate one's own cornea, adjusting for effects of cluster sampling (Items significant at the P < 0.05 level are highlighted in bold) (N=419)\***

<b>Variable</b>	<b>OR (95% CI)</b>	<b>P-value</b>
Age, per year	0.99 (0.98, 1.01)	0.487
Female sex	1.35 (0.84, 2.17)	0.217
<b>Knowledge score, (range: 0-12)</b>	<b>1.18 (1.04, 1.32)</b>	<b>0.008</b>
Ever had conversation about donation	1.16 (0.51, 2.63)	0.725
Considers corneal donation popular in society	1.57 (0.37, 6.72)	0.543
<b>Not feeling donation "damages the body"</b>	<b>1.91 (1.07, 3.43)</b>	<b>0.030</b>
<b>Willing to discuss donation</b>	<b>10.6 (3.35, 33.9)</b>	<b>&lt;0.001</b>
<b>Likelihood of giving consent to donate a loved one's cornea</b>	<b>10.3 (4.84, 21.8)</b>	<b>&lt;0.001</b>

OR: odds ratio CI: confidence interval

\* Age, sex and variables with P<=0.2 in table 2 were included in the multiple regression model.

**Table 5. Statements that play a role in not being willing to donate (Asked only of 255 persons not willing to donate their own corneas), and Statements and motivators that play a role in willingness to donate corneas (Asked only of 175 persons willing to donate their own corneas)**

<b>Characteristics</b>	<b>n</b>	<b>%</b>
		<b>(of 255)</b>
<b>Statements that would play a role in your decision to not pledge to donate your corneas</b>		
I do not like thinking about death	125	49.0
I am concerned (corneal) materials are being bought and sold on the black market	114	44.7
I am not sure of the reasons, I would just not feel comfortable about it	102	40.0
The body should be buried whole	89	34.9
My vision is not good enough to donate	56	22.0
I don't feel I have enough information to agree to donation	43	16.9
I don't want to give up such an important part of my physical appearance	29	11.4
Corneal transplants are sight saving, but not life saving	13	5.10
Eyes are needed in the afterlife	9	3.53
Other reasons	9	3.53
It is against my religious beliefs	6	2.35
		<b>(of 175)</b>
<b>Statements that play a role in willingness to donate corneas</b>		
Two blind people will be able to see again/be cured	100	57.1
Corneal donation allows something positive to come out of the donor's life	81	46.3
I feel like I am part of solving public health/ blindness problems in my community	73	41.7
I would gain merit that might affect my position in the next life	61	34.9
I would feel good about myself because of having made this decision.	50	28.6
Because helping others is an important part of being a good person	39	22.3
It is important that material are made available for research into causes of blindness	32	18.3
I would feel good about making the decision to donate on behalf of a loved one	25	14.3
It helps families of the deceased grieve	19	10.9
Other reasons	3	1.71
		<b>(of 175)</b>
<b>Motivators that play a role in willingness to donate corneas</b>		
Donor family support group	57	32.6
Thank you letter from the recipient	54	30.9
Thank you letter from the eye bank	47	26.9
Donor family ceremony/ celebration	21	12.0
Government publicity and education	21	12.0
Providing monetary compensation	18	10.3
Payment of medical expenses	16	9.14
Knowing corneas are being used legally	11	6.29

Receiving documentation for being a donor	2	1.14
Other	2	1.14

---